Kamisar, Hylda
Pollet, Dorothy

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THE VISUALLY AND PHYSICALLY
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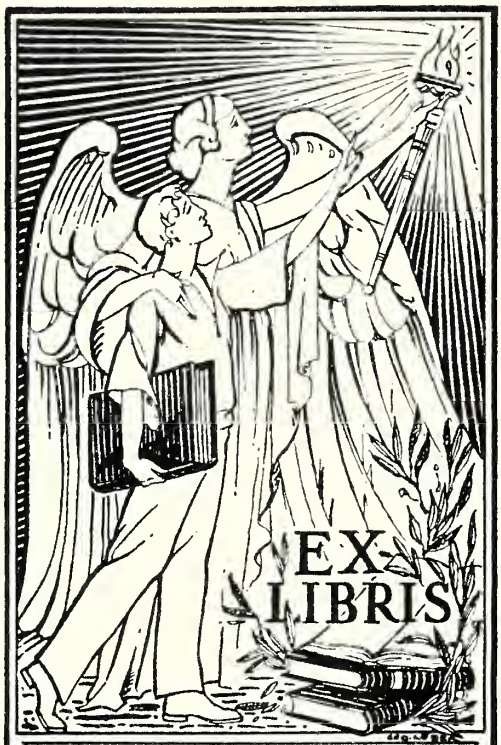

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The Library and the Community

Catholic Library World

Volume 46 May-June, 1975 Number 10

8/6/75, Letter pag

Hylda Kamisar and Dorothy Pollet

Those missing readers: the visually and physically handicapped

In recent years public libraries have had to cope with the problem of attracting new users of their services or risk a loss of community support. Faced with rising costs and the withdrawal of Federal funds, no library can afford to be content with a traditional middle class constituency that is itself turning to other sources of information and recreation.

In 1967, the National Advisory Commission on Libraries conducted a survey of public library use. Their conclusion was that only 25 percent of the population uses public libraries; nonuse was ascribed primarily to an indifferent public that is simply not book-oriented and to the failure of public libraries to find ways to overcome this indifference.[1] It is significant to note that the prevalent attitude of library administrators has been that nonusers *don't want* the services their public libraries offer; there is little recognition of the existence of those individuals who *want to but can't* use conventional library materials because of visual or physical handicaps. New evidence indicates that this group of persons who are unable to read print material because of a visual or physical handicap is substantial in size, comprising—even by conservative estimate—as many as 7.6 million individuals.

Potential readers among the handicapped population are not only those who cannot see well enough to read ordinary print; they are also people with normal vision who, because of some physical condition, cannot manipulate conventional print books. This second category includes the person crippled with arthritis for whom holding a standard book is painful or impossible, the hospital patient temporarily immobilized because of surgery, the neurologically impaired child who is unable to master the printed word.

Development of a National Network

A national program of library services to handicapped readers has existed since 1931. Administered by the Library of Congress Division for the Blind and Physically Handicapped, this program began by serving blind adults with braille books. Over the years it has been expanded to serve both visually and physically handicapped children and adults with library materials in a variety of special media. The philosophy upon which this program rests is that handicapped persons are entitled to library services of the extent and quality available to the general population and in whatever formats are best suited to their individual needs. Braille books and magazines are produced for blind persons who prefer this reading medium; however, at least 80 percent of the visually handicapped do not use braille, and for this audience the talking book was developed. In

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Pictures above: Soldiers Home, Washington, D.C.—Herbert Merrill, visually handicapped resident, assisted by Sherry Tolson, Library Technician; Montgomery County, Department of Public Libraries, Services for the Physically Handicapped, Rockville, Maryland—Cele Rubin and Grace V. Thompson browsing through braille books.

Potential readers among the handicapped population are not only those who cannot see well enough to read ordinary print, they are also people with normal vision who, because of some physical condition, cannot manipulate conventional print books. This article describes the services offered by the national program administered by the Library of Congress Division for the Blind and Physically Handicapped.

their lifetime, talking books (long-playing records of trade books) have undergone a series of innovations—starting in 1934 as 33-1/3 rpm discs, they went to 16-2/3 rpm, then 8 rpm; from 12-inch hard discs they progressed to 7-inch plastice flexible discs. Today books are also produced on cassette and in print/braille combinations. Over 20,000 individual works of music are available in braille and large type. Included in this free library service are specially designed record and cassette players and a variety of special aids such as speed control units, headphones, and remote control switches. For physically handicapped persons who may prefer printed material to recordings, a projected book system utilizing microfilm is being explored.

Under this national program, service to readers is provided on three levels:

Federal

With funds annually appropriated by Congress under Public Law 89-522, the Library of Congress Division for the Blind and Physically Handicapped selects and produces about 1,200 book titles and 70 magazines each year. These books, playback equipment, catalogs and publications are distributed to a network of 130 cooperating regional and subregional libraries throughout the Nation.[2]

State

The goal of one cooperating regional library in each State has been pursued since the inception of the program. Today there are 53 regional libraries (five of the more populous States have two regional libraries each, and four of the less populous States have no regional library but are served by other States under contract. The various regional libraries are located in State libraries, large metropolitan library systems like the Cleveland Public Library and the New York Public Library, and special agencies, as in the case of the Iowa State Commission for the Blind and the Perkins School for the Blind in Massachusetts. The regional libraries' function is to distribute reading materials directly to eligible persons. At this level, the service is provided primarily through a free mailing privilege.

Local

Today over 70 community library systems have been designated subregional libraries. Because of their closer proximity to users, subregional libraries in many instances can provide more personalized readers' advisory and reference services. In a typical subregional library, a collection of approximately 1,000 talking books, comprising the most recent releases, is maintained for

serving readers in the local area either in person or by free mail. Hundreds of public libraries, although not functioning as subregional libraries, maintain a demonstration collection of talking books and playback equipment in order to introduce the service to eligible local residents. Catalogs of available titles are also kept on hand to assist readers in selecting books.

The continuing growth of the service network reflects a corresponding growth in the number of readers. For the last several years, the rate of reader increase has ranged from 10 to 15 percent a year. An estimated 380,000 readers took advantage of the special library service in the annual period from July 1, 1972 through June 30, 1973. Yet contrasted with the universe of 7.6 million potentially eligible for these services, it is clear that many missing readers have yet to be reached.

Study Findings

Results are reported in two categories: I, Certain Eligibility, and II, Possible Eligibility. Category I includes those groups whose members all clearly meet the eligibility requirements of the Library of Congress program. Groups whose members are likely to be eligible are included in Category II.

I. Certain Eligibility

Severe Visual Impairment[4] (1,306,000)
1971 figure from the National Center for Health Statistics based on interviews of the civilian, noninstitutionalized population.

Institutionalized Blind (12,000)
Adults age 18 and over as measured by the 1967 Social Security Survey of Institutionalized Adults.

Absence of One of Both Arms or Hands (81,000)[5]
Based on data from the National Center for Health Statistics' National Health Survey, 1963-65.

Cerebral Palsy, Complete or Partial Paralysis (181,000)[5]
1971 figure based on health interviews by the National Center for Health Statistics.

Muscular Dystrophy, Completely Disabled (50,000)
Current estimate from the National Institute of Neurological Diseases and Stroke.

Quadriplegia (51,000)[5]
1971 figure from the National Center for Health Statistics.

Hemiplegia (199,000)[5]
1971 figure from the National Center for Health Statistics.

Total: 1,880,000

II. Possible Eligibility

Arthritis (857,000)[5]
1969-70 figure from the National Center for Health Statistics representing the number of persons unable to carry on their major activity because of arthritis or rheumatism.

Cerebral Palsy (Excluding Those Paralyzed) (569,000)
Current estimate of the United Cerebral Palsy Association.

Huntington's Disease (14,000)
Current estimate from the National Institute of Neurological Diseases and Stroke.

Identifying the Handicapped

Providing total service to visually and physically handicapped readers requires the development of both a service network involving libraries across the nation and effective techniques for identifying and reaching potential users. Public Law 89-522 passed by Congress in 1966 made eligible for this free library program any resident of the United States who is unable to read conventional print because of visual or physical impairment. In preparation for serving what would be a greatly expanded constituency, the Division for the Blind and Physically Handicapped sought data on the numbers of people with various physical handicaps that might prevent reading in a conventional manner. Yet no systematic study of the subject could be found. Faced with the necessity for planning a national program, the Division decided to use the figure of 2-3 million extrapolated from the limited available data. In light of the continuing need for accurate statistics on eligible readers, in August 1973 the Division undertook a comprehensive study of statistical sources as a necessary step in justifying and planning the scope of services at all levels. We began by identifying specific handicapping conditions that might affect a person's ability to read ordinary print, to hold a book or turn pages. The least difficult condition to pinpoint is blindness: obviously everyone in this category is unable to read print. But there is a wider group, the severely visually handicapped, which includes the blind as well as many others having a variety of eye conditions that make reading extremely difficult. Within the broad category of the physically handicapped, the distinction between those with a particular condition that results in an inability to read and those whose reading ability is unaffected is far more difficult to make. Certain conditions will without question render a person incapable of holding a book or turning pages—quadriplegia, for example. But diseases such as multiple sclerosis are characterized by slow, uneven progression with periods of remission. Knowing the total number of multiple sclerosis victims does not tell us how many are unable to read or hold a book at any given time.

Learning Disabilities (1,542,000-2,570,000)
According to the current estimate from the Association for Children with Learning Disabilities, 3-5% of the school population is neurologically impaired.
Mental Retardation (1,525,000-6,100,000)
The National Association for Retarded Children estimates that 3% of the population (6.1 million) should be identified as mentally retarded before they are 15 years old. According to the President's Committee on Mental Retardation, only 25% of all mental retardation can be attributed to a biomedical factor (1,525,000). However, under Federal legislation like the Developmental Disabilities Services and Facilities Construction Act of 1970, mental retardation is regarded as a physical handicap.
Multiple Sclerosis and Related Diseases (500,000)
Current estimate of the National Multiple Sclerosis Society.
Muscular Dystrophy (Excluding Those Completely Disabled) (150,000)
Current estimate of the National Institute of Neurological Diseases and Stroke.
Myasthenia Gravis (30,000)
Current estimate of the National Institute of Neurological Diseases and Stroke.
Paraplegia (102,000)[5]
1971 figure from the National Center for Health Statistics.
Parkinson's Disease (200,000)
Current estimate of the National Institute of Neurological Diseases and Stroke.
Spina Bifida (27,500)
Current estimate of the National Institute of Neurological Diseases and Stroke.
Spinal Cord Injury (125,000)
Current estimate of the National Institute of Neurological Diseases and Stroke.
Tumors of the Brain and Other Parts of the Nervous System (140,000)
Current estimate of the National Institute of Neurological Diseases and Stroke.

Total: 5,781,500-11,384,500

Further problems are encountered in the instances of mental retardation and learning disabilities. Is mental retardation physically based? Undoubtedly it is in some cases, but in how many? Authorities in the field of learning disabilities vary in their use of nomenclature to the extent that 40 different terms have been used to apply to the same disorder.[3]

We eventually settled on a list of 16 physically handicapping conditions that are likely to affect the ability to read. Included were only those conditions of sufficient prevalence as to be statistically significant. Selecting mutually exclusive categories and grouping related conditions together helped to minimize the inevitable overlaps in data collected by diverse sources and exhibiting wide variation in categories. Information on the numbers of paraplegics and quadriplegics has been included, however, even though the data overlap to an unknown extent with that for diseases and conditions which can cause paralysis. When particular age groups and elements of the population were excluded from certain data, we tried to obtain figures for those missing elements elsewhere. Where this was impossible, the limitations of the data were stated, but no attempt was made to compensate for them statistically in the final tabulation. Breakdowns of the data by age, sex, geographic region and other factors are included in the study whenever possible.

All known sources of current national data on blindness, severe visual impairment, and the other handicapping conditions identified were consulted. These sources include government agencies such as the National Center for Health Statistics of the U.S. Public Health Service, the National Institute of Neurological Diseases and Stroke, the Social Security Administration, and private and voluntary organizations such as the National Society for the Prevention of Blindness, National Association for Retarded Children, and National Multiple Sclerosis Society. The principal secondary source used was the National Health Education Committee's biennial compilation, *Facts on the Major Killing and Crippling Diseases in the U.S.* Finally, an extensive MEDLINE search at the National Library of Medicine was conducted, to ensure that no additional source of data went undetected.

Study Implications

An obvious implication of this study is the need for further research. We must learn who the handicapped are, where they are and what their special needs are before long range planning of library services can take place. There is clearly a need for closer cooperation with the agencies that are responsible for gathering data on the handicapped population. In its national health surveys of the civilian, noninstitutionalized population, the National Center for Health Statistics includes a question about the inability to read newsprint. From this survey come our statistics for the number of persons who are severely visually impaired. A similar question asked of persons with other physical handicaps would be an invaluable

source of additional data on this group. On the local level, registers of blind persons, records of low vision clinics, schools, hospitals, rehabilitation agencies and chapters of voluntary health agencies can be of assistance in identifying handicapped persons and in estimating their approximate numbers. Unfortunately, the reliability of the data obtained in this manner is open to question because these agencies themselves often have to resort to gross estimates derived from secondary sources.[6]

Even though we cannot yet state exact numbers of potential handicapped readers on the local level, we now know that the potential for service to a sizeable body of readers exists everywhere. An excellent example of what a library on the local level can do to locate and serve visually and physically handicapped readers in its community is provided by the Huntington Public Library in Huntington, New York, one of 77 subregional libraries in the Library of Congress network. Their Reading for the Handicapped program offers talking book service to individuals, schools, nursing homes, hospitals and the homebound throughout Suffolk County. A specified number of every talking book produced by the Division for the Blind and Physically Handicapped is mailed to Huntington on a continuing basis. Beyond the basic service of circulating these books, the program has expanded to include readers' advisory service, procurement of special materials on tape for handicapped students, finding readers and letter writers for the blind, and getting social agencies and newly handicapped persons together.

Huntington estimates its potential readership among the handicapped to be about 41,000. In August 1972, the library's first month for this service, a total of 23 books was circulated. By July 1973 circulation had grown to 2,612; and by Fall 1973 an average of 108 new readers a month were joining the program. Success has come through a combination of imagination, innovation and a spectacular ability to convince the community that this program is an integral part of good library service. Community support was recently expressed in financial terms when County officials made a $20,000 grant to the library to be used exclusively for library services to the handicapped.

Subregional Library Programs

Communities that are not part of large urban centers like Huntington are also establishing successful subregional libraries. An example of such community is Virginia Beach, Va. The program for visually and physically handicapped readers at the Virginia Beach Public Library

currently serves about 650 readers. Between November 1972 and November 1973 circulation of talking books doubled, growing from 1000 to 2000 talking books a month, and circulation of cassette books went from zero to 150 a month. Some large type and braille books are also circulated by this library. Special projects initiated by the library include courses in make-up and homemaking for blind women, a large type newsletter to patrons, and volunteer-assisted activites ranging from transcribing to home visits to the elderly. Virginia Beach has also been successful in obtaining some financial assistance: the Lions Club helped with a large type typewriter, braille typewriter, and Perkins Brailler, and the State provided a $15,000 grant for hiring handicapped employees for the program.

Each subregional library in the network works closely with the regional library in its State. The subregional library maintains a relatively small collection of talking books and keeps daily contact, if necessary, with the regional library, drawing upon the latter's larger collection via inter-library loan. The regional library, in turn, can make use of the even greater collection of materials housed in the headquarters of the cooperating network, the Library of Congress Division for the Blind and Physically Handicapped. The benefits of this cooperating system to readers is a full range of library services; to participating public libraries it is an opportunity to find and serve those missing readers. □

FOOTNOTES

1. *Libraries at Large.* New York, Bowker, 1969. p. 49.

2. Library of Congress Division for the Blind and Physically Handicapped. *Directory of Library Resources for the Blind and Physically Handicapped.* Washington, 1974. [in process]

3. Cruickshank, William M. "Some Issues Facing the Field of Learning Disability," *Journal of Learning Disabilities,* August-September 1972, p. 7.

4. Defined as the inability to read newsprint even with corrective lenses.

5. Represents the civilian, noninstitutionalized population. Corresponding figures for institutionalized population unavailable.

6. *Library Services for the Handicapped in Ohio.* Kent, Ohio, Kent State University School of Library Science, 1968. p. 9.

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